



Family Caregiver

Sharing Information & Giving Support to Hawai'i's Family Caregivers

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Long-distance Caregiving

by Charles Kenyon

I'm a 59-year old man from Philadelphia, Pennsylvania, who spends a considerable amount of time in Honolulu. I have a sister, 65, and a brother, 49, who are at least as involved as I am in our caregiving roles. Like many "baby boomers," I've had considerable experience in caregiving with both parents. My father died of bladder cancer in 1992. During the last year, while on sabbatical from teaching, I saw Dad slowly weaken. At the time, Mom, who

was almost a superwoman, did everything for Dad and did it proudly.

Before he had chemotherapy, I often drove both Mom and Dad to Fox Chase Cancer

Center for doctor appointments and visited him daily during his few lengthy stays. During his last few months, Dad had in-home hospice service and Mom took care of his every need. I was able to visit him almost every day. Most days, he was sharp, fun to talk to, and clearly appreciated all of us visiting him. It was only in the last week that he went into a coma. All we could do was hold vigil until he passed from



this world.

Mom is still strong, healthy, and mentally sharp for her 89 years. She has severe arthritis, which makes walking painful and limits movement in her shoulder. She also has short-term memory problems after surviving two minor strokes. Despite these limitations, she still manages to get around (with cane and walker) and keeps her wonderful sense of humor. While Mom, like many seniors her age, would be happy to never leave the house, she continues to go out with us frequently. She is a loving mother who wants us to enjoy life and not spend all our time worrying about her. She totally supports my

desire to travel and does not want to be a burden in any way. She now has a device she rides up to the second floor of the house. She is quite happy staying in the home she has lived in since 1952, and is clearly at peace there.

My brother, sister, and I visit Mom as often as possible. My sister provides the most help. I take her out to lunch and run her errands often whenever I'm home. I know if something ever happened to Mom, I would stop traveling and be there every day to help as needed. But I am pleased so far, by her level of self-sufficiency. I call her daily to check on her. She's an incredible lady!

Aging and Disability Resource Centers (ADRC)

The Hawaii Executive Office on Aging (EOA) was recently awarded \$800,000 from the U.S. Department of Health and Human Services' Administration on Aging and Centers for Medicare and Medicaid to develop an Aging and Disability Resource Center (ADRC) in Hawai'i over the next 3 years. The ADRC Project is part of a national effort to establish a single entry point to long-term care resources in the community, including the Medicaid program. The national and state's vision is to have highly visible Resource Centers where people can turn for assistance and information on the full range of long-term care options. This includes in-home, community based services, nursing homes and other programs that are designed to help the elderly and individuals with disabilities.

Hawai'i's ADRC project proposal focuses on three goals: (1) Start a pilot one-stop Resource Center in Hawai'i County that may serve as a model for other sites throughout the state; (2) Develop strategies for statewide access such as telecommunications and website; and (3) Seek resources for a one-stop Resource Center in Honolulu. The overall design is to build the ADRC from the core functions of the local Area Agencies on Aging.

The Mayor and County Council of Hawai'i County have identified the ADRC as one of their priority projects and will support the project development on the Big Island with additional county funds. In collaboration with other aging and disability agencies, Hawai'i County will relocate services and providers in a centralized facility, offering a one-stop shop for information and resources. The Resource Center will offer information, counseling, referrals, assessment and eligibility functions for both publicly and privately funded services targeting two groups—the elderly over age 60 and people with physical disabilities.

Honolulu's Elderly Affairs Division office will participate in the statewide planning with the goal of establishing an ADRC on O'ahu as the second site

for the State, with more sites to follow in the remaining counties and islands.

The success of the ADRC Project has several implications for the State. Consumers will have access to a comprehensive, highly visible and trusted source of information on the full range of in-home, community-based and institutional services and programs for the elderly and those with disabilities. This will minimize confusion, enhance individual choice and support informed decision-making. Aging baby boomers and other consumers can obtain information for long-term care planning, which is one of the ADRC's goals.

The Center can serve as the entry point of publicly administered long-term care services, including Medicaid community-based waiver programs, nursing homes and the Older Americans Act and other state programs. It may even play a role in assisting consumer access to the new, expanded QUEST managed care program for the aged, blind and disabled population, which is scheduled to begin in 2007. Finally, the

ADRC can improve the ability of State and County governments to manage resources and monitor program quality through the Center's centralized data collection and evaluation process. For more information, please contact Pat Sasaki, Director of EOA, at 586-0100.



E LOA KE OLA



MAY LIFE
BE LONG

The Executive Office on Aging is the state agency whose mission is to promote dignity and independence of older adults, and to help prepare for the rapid expansion of Hawai'i's aging population.

Phone: 808-586-0100
www4.hawaii.gov/eoa

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We provide access to our activities without regard to race, color, national origin (including language), age, sex, religion, or disability. Write or call EOA or the DOH Affirmative Action Officer at Box 2278, Honolulu, HI 96801 or at 808-586-4616 (voice/tty) within 180 days of a problem.

Caregiver Services: Where Do I Start?

The best place to start in getting information on caregiver services in your community is your county office on aging. They can be reached at the following numbers:

Honolulu Elderly Affairs Division
523-4545

Kaua'i Agency on Elderly Affairs
241-4470

Maui County Office on Aging
270-7755

Hawai'i County Office on Aging
961-8600 (Hilo)
327-3597 (Kona)

Preparing for the Holidays

by Keoni Kealoha O. Devereaux, Jr., PhD
Vice President of Programs
Alzheimer's Association - Aloha Chapter

For most families, holidays are filled with opportunities for togetherness, sharing, laughter, and memories. But for families coping with Alzheimer's disease and other related disorders, holidays also can be filled with stress, disappointment and sadness.

One of the first things you should do is realize that the holidays may no longer be the same as in the past and adjust your expectations accordingly. No one, including yourself, should expect you to maintain every family tradition and event. Give yourself permission to do only



Keoni Kealoha O. Devereaux, Jr.



what you can reasonably manage. If you've always invited 15 people or more to your home for a seven-course dinner, consider inviting five or less for a simple, yet meaningful and intimate meal. Ask others to bring "potluck" dishes or to host the meal at their home. Those close to

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Alzheimer's Disease Caregiver Support Groups

Although it is common to feel alone as a caregiver and to think that no one understands what is happening to your life, coping with Alzheimer's Disease or a related disorder does not have to be a lonely experience. Participating in a family support group can help by giving you a chance to share your feelings with others who understand because they too have a loved one with dementia. Support groups provide a sense of community. It's a place where you can go and, without saying a word, be understood. It's a bond, a community, a trust you have for each other. Caregivers meet in a non-judgmental, confidential, and sympathetic environment to share coping techniques, knowledge of the disease, awareness of community resources, and fellowship. Below please find a list of support groups that meet monthly across the state. These support groups are sponsored by the Alzheimer's Association - Aloha Chapter.

O'ahu

Prior to attending any group, please call 591-2771 for questions & possible changes.

Aiea/Pearl City
St. Timothy's Episcopal Church
98-939 Moanalua Rd.
3rd Mondays, 7:00 pm

East Honolulu
Holy Nativity Church - Glantz Hall
5286 Kalaniana'ole Hwy.
2nd Mondays, 7:00 pm

Kailua
Hope Adult Day Care Center
77 N. Kainalu Dr.
1st Saturdays, 12:00 pm

Kaneohe
Aloha Nursing & Rehab Centre
45-545 Kamehameha Hwy.
2nd Saturdays, 10:00 am

Makiki/Ala Moana/Ward
Alzheimer's Office - Ward Warehouse

1050 Ala Moana Blvd., Bldg. D15
2nd Thursdays, 7:00 pm

Makiki/Ala Moana/ Ward
Alzheimer's Office - Ward Warehouse
1050 Ala Moana Blvd., Bldg. D15
3rd Saturdays, 9:30 am
Please call to RSVP

Maui, Lana'i & Moloka'i

Please call 808-242-8636 for dates and times.

Hawai'i

Chris Ridley is the facilitator for all Island of Hawai'i support groups. She can be reached at 808-981-2111.

Hilo
Hawai'i Island Adult Care
34 Rainbow Dr.
Second Fridays, 9:00 am

Hilo Lagoon, Room 145
101 Aupuni St.
Last Mondays, 5:00-6:30 pm

Keaau
Keaau Bay Clinic
16-192 Pilimua St.
Last Wednesdays, 9:00 - 10:30am

Pahoa
Pahoa Family Health Center
15-2868 Pahoa Government Road
2nd Mondays, 10:00 - 11:30 am

Waimea
Tutu's House
64-1032 Mamalahoa Hwy, #305
Third Tuesdays, 11:00 am - 12:30 pm

Kaua'i

Call 808-821-1776 for information.

Lihue
Lihue Neighborhood Center
3rd Tuesdays, from 5:30 - 7:00 pm

Hanapepe
Hanapepe Neighborhood Center
3rd Thursdays, from 6:30 - 8:00 pm

Kilauea
Kilauea Neighborhood Center
1st Thursdays, from 9:00 - 10:30 am



H O N O L U L U

EAD Observes National Family Caregivers Month

The Elderly Affairs Division was among the many Area Agencies on Aging across the nation to observe November as National Family Caregivers Month. Honolulu Mayor Mufi Hannemann issued a proclamation in recognition of the many challenges family caregivers face (*see photo above*). The proclamation also raises awareness about programs and services that support family caregivers.

The Mayor thanked all caregivers for their commitment and caregiver organizations for their support, stating, "Caregivers are the backbone of our long-term health care system.... It is a time to recognize, thank and honor family caregivers for their contributions."

The number of unpaid family caregivers in Hawai'i is estimated at over 190,000. These unsung heroes provide care to loved ones who have a disability, who are chronically ill or who are elderly. At the same time, many caregivers work and are raising their own families.

As the aging population continues to grow and health care costs continue to rise, the need for caregivers will even be greater. Will Hawai'i be prepared for this growth? These are the issues policy makers will need to address. Advocates will be pressing legislators in the next legislative session to pass

bills that will more fully support family caregivers.

H A W A I ' I

Carousel of Care Caregiver's Conference

Approximately 150 people were in attendance at the 7th Annual Carousel of Care Caregivers's Conference held on November 30, 2005. The keynote speaker was Dr. Kalani Brady, followed by eight other sessions in the morning. Afternoon sessions were focused on pampering the caregiver and relaxation techniques. Caregivers were treated to massages, healing touch, flower therapy, a tea ceremony and art therapy.

M A U I

Maui County Celebrates National Family Caregiver Month

On November 4, 2005, the Council of the County of Maui adopted a resolution recognizing November 2005 as National Family Caregivers Month. Maui County Council member, the Honorable Danny Mateo, introduced the delegation that "received" the Maui County Council's resolution (*see photo, right*). The delegation included Sandy Freeman, Executive Director of Maui Adult Day Care Center (MADCC), Kathleen Cunch, MADCC Caregiver Support Group Program Coordinator, and John Tomoso, Coun-

Top left: Self-care session—a tea ceremony at MOA Hawai'i. Top right: The Regency at Hualalai, the only assisted living facility on the Big Island, had a display at Hawai'i County's Resource Fair. Above: Pamela Cunningham of Sage Plus shares information on the Medicare Part D prescription drug plan at the Resource Fair.

ty Executive of the Maui County Office on Aging. Mahalo to the Maui County Council and its hard working staff for this commemoration and resolution. The Honorable Mayor Alan Arakawa proclaimed and signed his Proclamation at Maui County's Fourth Annual Caregiver's Conference on November 19, 2005.



It worked for me

with Karen Koles



The Holiday Season often means rich foods, changes in our dietary habits and sharing new and different dishes.

This sharing should not spread to our loved ones on a restricted diet.

One obvious example is sharing desserts with a diabetic.

Another example is sharing rich foods with those who have a sensitive digestive tract or on a bland diet. Consequences such as diarrhea and upset stomach could follow.

Please also remember that mochi, a sticky dessert made of rice flour, can be very dangerous for our loved ones. It should be considered a seri-



ous, life-threatening choking hazard because once swallowed, it will not melt like a large spoonful of ice cream, jello or even an ice cube. Even though mochi may have traditional significance in your family, it might be best to avoid any form of this food for your loved one.

On another note, have you pre-

pared for New Year's fireworks and air pollution? A friend who suffers from severe respiratory problems uses New Year's Eve as a family celebration by checking into a high-rise hotel to watch everyone else's fireworks from inside an air-conditioned room. If your loved one cannot be easily transported, you may want to invest (buy, borrow or rent) in several portable room air purifiers. Close all the windows and leave the bedroom door partially open to allow for fresh air to enter the room. Your loved one may find it comforting to have a radio or the television to help mask the noise of the fireworks. If possible, spend the evening "talking story" about past New Year's celebrations with your loved one. Incidentally, your pets might benefit from this set-up, too!

On a personal note: I am well on the road to recovery and appreciate all of your prayers, phone calls and get-well cards.

Disclaimer: The suggestions in It Worked for Me were found to be helpful by contributing caregivers and are not to be interpreted as fact or intended to guarantee similar results.

Preparing for the Holidays

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you and your loved one may welcome this opportunity to help.

To avoid unpleasant surprises or hurt feelings, you may want to discuss holiday celebrations with relatives and close friends ahead of time. Make sure that all family members understand the situation and have realistic expectations for their visit. After months or years apart, family members may be alarmed to see the changes in their loved one. They may be shocked by the person's appearance or behavior, and disturbed by the memory deterioration. They may even suggest that you are not properly providing care for their loved one. You may wish to familiarize them with the situation in advance by calling and sending a letter that makes these points:

"While we're looking forward to your visit, we thought it might be helpful if



you understood our current situation before you arrive. Because Mom (or Dad) sometimes has problems remembering and thinking clearly, her/his behavior is slightly unpredictable. Please understand that she/he may repeat conversations and may not remember who you are or may confuse you with someone else. Please don't feel offended by this. She/he appreciates your company, and so do I."

Enjoy the moments when meaningful communication and interaction occur, however short and infrequent they may be. If your loved one can engage in conversation with a grandchild for only two minutes, treasure those two minutes, rather than measuring it against the entire

four-hour holiday gathering.

Involve the person with Alzheimer's disease throughout all stages of holiday preparation. Pick manageable activities: wrapping gifts, setting the table, or preparing simple foods such as appetizers. Avoid asking the person to do more complicated and potentially frightening activities such as hanging blinking lights. Maintain your loved one's normal routine as much as possible in order to limit

disruption and confusion. For example, if the person goes on a daily walk, try to continue that practice, even on a holiday.

Build on past traditions and memories. Your family member may find comfort in singing holiday songs, for example. But also experi-



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Be Wise...Immunize!

If you provide care at home for a chronically ill or disabled friend or relative, you're often "on-call" 24 hours a day, seven days a week. Sometimes the prolonged stress and physical demands can strain even the most capable person. You want to provide the best possible care, but in the process you can pay a high price by neglecting your own physical and emotional health. In fact, caring for yourself is one of the most overlooked elements of being a caregiver.

Caring for yourself might sound selfish when someone is ill and needs your help. But is it really self-

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ish? Of course not. Without your good health, your loved one's health can suffer. If you become ill, you may infect your loved one, make caregiving errors or poor decisions. You may have to resort to more costly alternatives for care, or be separated from your loved one if you need to be hospitalized.

There is, however, one thing you can do right away to stay healthy. It's quick, easy and effective. Immunize yourself against some of the most preventable infectious diseases.

Why start with immunization? Up to 40,000 American adults die each year from vaccine-preventable diseases. The Centers for Disease Control and Prevention has recommended immunizations for professional healthcare workers since 1981. Immunizations are becoming standard for health professionals, and they should be for you too!

With immunizations, you have protection against certain diseases. The most important immunizations you should have are against influenza, pneumococcal disease and tetanus. Influenza and pneumonia are the fifth leading cause of death in older adults; more than 90% of those who die from flu and pneumonia are people over 65 years of age and older. Tetanus, although rare, tends more often to be fatal for older adults.

You can get these vaccines from your family doctor. In addition, the Department of Health or community hospitals may hold special clinics to offer influenza, pneumococcal and other vaccinations. Sometimes senior centers and pharmacies offer them, and during influenza season, you may even see clinics set up in shopping malls, grocery stores and other places. Costs may be covered by Medicare Part B, Medicaid or your private health insurance or HMO.

Your sense of responsibility, of doing the right thing, of "giving back" to someone who once took care of you, can only come about if you remain healthy. So take special care



of yourself. There are a number of ways to improve and maintain your health, seek out caregiver support services in your community, join a support group either in-person or online, take breaks from caregiving, get rest, get exercise or get others to help. But before you do that, be wise...and IMMUNIZE!

(Adapted from the Administration on Aging Factsheet, September 2005)

Preparing for the Holidays

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ment with new holiday traditions, such as renting seasonal videos that the less active person may enjoy. Sign your loved one's name to some of the presents you give to other family members. This will help the person contribute to the holiday celebration. During the holiday gathering, be alert for signs of agitation and frustration in your loved one. Don't seat him or

her in the middle of a noisy room, as it may result in over-stimulation and agitation. The person with Alzheimer's may be able to focus better on questions and comments in a corner area of the room where there are fewer distractions.

But most of all, give yourself a gift. Caregiving is a labor of love. Those who provide care to others often overlook their own needs, believing that they must take a back seat to their loved one. Always remember—take care of yourself as a caregiver so you can continue to give care!



Tutu's Corner

Free Health Insurance for Kids in Kinship Care

Hawai'i Covering Kids conducts extensive outreach and enrollment activities throughout the state to educate grandparents raising grandchildren, among other groups, about children's public health insurance. An adult relative (*e.g.*, auntie, uncle, cousin, *etc.*) or adult with a hanai



child can apply for QUEST and Medicaid for children living in their homes. If only the child wants health insurance, Med-QUEST will not count household assets or the guardian's income. Below are more details to help families:

1. What is the difference between QUEST and Medicaid?

Medicaid Fee-for-Service (Medicaid) is generally for people who are certified blind or disabled and/or over 65 years old. Health care providers are paid directly for their services. QUEST is for those



under 65 years old, not certified blind or disabled and not in a public institution. It uses managed care plans—currently AlohaCare, HMSA, and Kaiser.

2. What health care services are provided by QUEST and Medicaid for children?

QUEST and Medicaid cover regular check-ups, doctor visits, emergency care, eyeglasses, immunizations, counseling, prescription medicines, and dental benefits.

3. How do I apply for children living in my home?

Guardians can request an application by calling 211 (free phone call from all islands) or by visiting www.coveringkids.com. Med-QUEST's application "For Children and Pregnant Women Only" makes it easy to sign up. However if someone needs help, she or he can ask the 211 operator for an outreach worker in his or her geographic area who can provide assistance.

5. Who should be listed in Question 1 on Med-QUEST's application?

List information about the adult

in both Questions 1 and 3A, because this is the person who will receive all correspondence from Med-QUEST.

4. If a guardian applies for a child living in the home, is legal guardianship required?

No.

6. If an adult relative or adult with a hanai child applies for a child living in her/his home, what income should be listed on the application?

Only list the child's income. If the child has no income, check Question 4A and explain the child is living with the adult relative or adult friend.

7. Does Med-QUEST require information on an absent parent?

If the only person who wants health insurance is a child or pregnant woman, no information is required about an absent parent. In fact, Med-QUEST's application "For Children and Pregnant Women Only" does not have any questions about absent parents.

Medicare Part D Checklist

The Medicare Part D drug benefit began on January 1, 2006. May 15, 2006 is the deadline to enroll if you are currently eligible for Medicare.

If you wait to enroll after May 15, 2006 and you are currently eligible AND you don't have coverage as good as Medicare's (called "creditable coverage"), you could pay higher prices and you may not be able to get the benefit when you need it. (The penalty of waiting is 1% for every month that you delay enrollment, and you have one opportunity to enroll each year from November 15 - December 31.)

The plans all have different formularies (the list of drugs that they cover) and different participating pharmacies. You may not be able to go to a non-participating pharmacy or you may have to pay out of pocket or higher prices; check your plan's summary of benefits.

Members with Medicare and full-benefit Medicaid (where Medicaid paid for their drugs in the past) can change plans on a monthly basis.



All other members with Medicare have one opportunity to change plans between January 1, 2006 and May 15, 2006.

Checklist for my family member's Part D Plan:

☐ Did you notify the physician(s) on

which Part D plan you have enrolled your family member(s) in?

☐ Do you have the plan name, phone number, and hours of operation easily accessible?

☐ Due to the privacy act, did you need to fill out a form authorizing you to speak on behalf of your family member (you may not be able to ask questions about their individual coverage)? Check with the plan for what is required.

☐ What is required by the Medicare Part D Plan for the exception procedure in case their Medicare-approved drug is not covered by the plan's formulary?

☐ Have you done a cost comparison of the participating pharmacies in your plan? (All pharmacies may not charge the same price.)

☐ Did you start a file to keep all the receipts for prescription drugs so you know when your family member has met the deductible, coverage gap and catastrophic coverage?

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